Pallium Canada

Webinar Q&A
Essential Conversations: Utilizing Advance Care Planning & Serious Illness Tools During COVID-19 and Throughout the Patient Journey – Wednesday May 13, 2020 @ 6pm ET

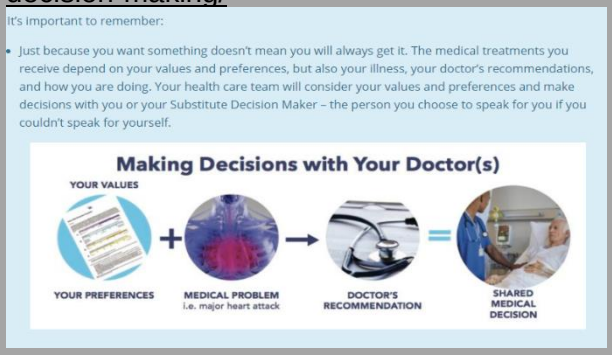
Question	Answer
Namgyal 06:30 PM **Q. In terms of a goals of care (GOC) discussion policy, can we say a GOC discussion must be initiated with every patient in the healthcare organization but discussions urgency increases for patients who are at risk for health deterioration?**	Jessica Simon: Some organizations do have policies that promote initiating conversations early in the course of treatment and for these. Assessing clinical appropriateness, including urgency of need for discussion, is remains a key element of clinician judgement. We have to be flexible in our approaches, titrating to patients' preferences in talking or not talking about what matters to them and ensure conversations are therapeutic and not forced by policy or the health care professional's (HCP) agenda. The Serious Illness Conversation Guide asks the HCP to check in with the patient and ask permission to proceed before and during the discussion and that is one of its helpful elements. Jeff Myers: For Ontario (which does not have a standardized set of care designation) ACP should occur for every person who is healthy. ACP should also occur for every person with serious illness and a focus for the conversation should be on illness understanding. A GOC discussion then occurs leading up to any decision-making & consent process. Cari Hoffmann: Advance Care Planning is for all healthy adults – and the things we think, reflect, decide & record typically look different if we are healthy or facing a serious illness or our end of life. Your question has me reflecting on this very point & I suggest we collectively ensure that the differences of the conversations that take place throughout the ACP processes.
Kate 06:39 PM **Q. These are such valuable conversations, but in my experience even when documented this can be overlooked (especially if nurse contacting an on-call doctor, or in an emergency situation). I wonder if**	Jessica Simon: Yes documentation alone isn't always enough. Helping patients know it is OK to bring up what you've talked about together with future health care providers and also providing direct (e.g. telephone) handover on time sensitive or nuanced issues to on-call, receiving physicians, ED physician, Family physician at discharge can help enhance safety in transitions of care. Jeff Myers:

people could share techniques/methods they use to make this understanding/insight accessible to other health care providers who have to interact with your patient in different circumstances, that you feel have worked the best.	Formal documentation in healthcare records is no doubt a crucial component of any effective ACP/GOC system however because of the complex challenge of multiple electronic health systems, we may do better at a system level if patients and their substitute decision makers are the holders of info. Either informally or formally via personal medical info system. Cari Hoffmann: Asking questions of the patient at all touch points in the system & documenting is key, as stated. I also believe asking value based questions of SDMs even in a crisis is very beneficial. “If your mom could tell us what to do right now, what would she say?” Ensuring that throughout the ACP process, persons & those that matter to them are prepared is crucial – that could be having the paperwork readily available and knowing what route to go.
Joanne 06:43 PM **Q. My patient does not want any extraordinary measures taken (he has advanced MS). His wife adamantly wants to sustain his life with all means possible. He doesn't want to upset her. Any helpful hints?**	Jessica Simon: This is such a challenging situation. Making time to elicit and listen to each person’s concerns can be helpful. In addition, specialist palliative care providers are happy to support patients, families and HCP through this sort of complex communication. We use the family meeting as a key intervention to facilitate a person and their loved ones exploring each other’s worries or fears and finding a way forward together. Jeff Myers: Agree, this is very challenging and also agree with Jessica’s points. I would add that to the patient I’d say that although upsetting his wife would be difficult, far more challenging is the situation of the pt requiring emergent or critical care. If he has decision making capacity and decides against certain interventions, this may come as a shock to his wife. If he does not have decision making capacity, his wife will make decisions from perspective of sustaining life at all costs. It is much less challenging addressing these things when there is time to digest information and in a structured, humane way. Cari Hoffmann: Agree with the points above. Involving social work or spiritual care would also be beneficial – as well as any other people that matter to this gentleman. Tough situation for sure!
Andrew 06:45 PM	Cari Hoffmann:

Q. In NS we have a special patient program with EHS in which once a person makes their GOC known clinicians can register them in the ambulance system so they can access their wishes and code status when going to the call. It is limited in that the person that phones the ambulance has to divulge that they are enrolled in the program. The NS system with EHS is complimentary to the Personal directive.	Yes, NS health care system is organized differently than most in Canada in that, EHS is part of the system. In Fraser Health in BC, we have a community greensleeve (plastic folder with magnets) that goes on your fridge & holds your ACP & GOC info. Should EHS arrive, they check for any wishes/instructions. Not perfect by any means. We also have an EHR within acute care that holds ACP & GOC documentation in a single source of truth. It's viewable in other care settings such as home health. I believe that many EHR systems across the world are challenged with accessible current info.
Anonymous 06:46 PM **Q. What methods exist for recording/transferring/accessing records of goals of care discussions done in another setting, across the country? E.g. an emergency doc accessing family doctor "GOC" note in virtual chart, or transfer of GOC record from long term care home to hospital.**	Jeff Myers: Apart from an educated and self-reliant patient and family, no national formal electronic mechanism exists for transferring patient information. I think such a system would actually be unwise precisely for the examples listed in the question as consent is needed at the time of every decision. Previously stated goals can serve only as helpful info to refer to during decision making. Cari Hoffmann: Thanks Jeff and agree there is no national electronic system within health care. In Fraser Health in BC, we have scanning & archiving in a single source of truth in the EMR, as noted above. Community clinics & GPs can fax into acute medical records and we can upload them into this area. It is then viewable in other care settings. This is a challenging area and one that is not solved easily. I am also aware that MyCHART, an online website where patients can create and manage their own personal health information, may have some abilities for recording/transferring/accessing/sharing. Sunnybrook & Fraser Health have launched this platform, maybe in other areas as well, perhaps this is the way of the future? https://sunnybrook.ca/content/?page=mychartlogin-learnmore https://www.fraserhealth.ca/patients-and-visitors/mychart-patient-portal#.XsWEomhKi70
Diana 06:49 PM **Q. What is the best approach to a patient that has talked to their GP, but the GP has not fully explained the ACP to them. Yet we are working weekly**	Jessica Simon: If you are able to support your GP colleague who may not have the time, comfort or skill to pick up where they left off they will likely be grateful. For example you might walk the patient through on-line resources, or recommend a video, for your jurisdiction that explore ACP more fully see advancecareplanning.ca. Be sure to document the outcome of your discussions and share that with the GP. If there is a

with these patients. Example Renal failure yet the individual wants the full resuscitation.	mismatch between the patients stated goals and their medical orders don't be afraid to pick up the phone and share with their GP what you are hearing from the patient. Cari Hoffmann: I think this further highlights the need & beauty of interdisciplinary care. I would suggest nursing, social work etc. get involved in conversations, to explore this. My sense is there is often a disconnect with the need for full resuscitation to receive any care. I often recommend the conversations clearly outline what treatments are beneficial & being offered, and those treatments that are not beneficial & not being offered.
Zahraa 06:49 PM **Q. Can we have GOC signed electronically? My understanding is that they needed to be physically signed. Thanks**	Jessica Simon: May depend on your jurisdiction and healthcare system. Verbal orders with repeat, faxed signed orders etc. may be acceptable in your area, if they are for other orders e.g. prescribing medication. Cari Hoffmann: Two Health Authorities in BC have experience with this. I have emailed them to understand their practice.
Kelly 06:49 PM **Q. How do we manage our response when the patients' goals and values will not be able to be met due to the epidemiology of COVID and what our guidelines are to keep patients safe in our centers. I.e. "I want to be able to see all my kids "but can only have perhaps one person in center at a time per PHO COVID guidelines. It's hard for patients to understand by times.**	Jessica Simon: This is so very hard for patients, families and staff. Your compassion in providing a space for the grief, anger and whole range of emotions that COVID-19 visiting restrictions produce is valued and we also need to extend that compassion to ourselves.
Carolin 06:52 PM **Q. We have seen reluctance to enter our PCU because, in part, of the visitor restrictions.**	Jessica Simon: As above: This is so very hard for patients, families and staff. Your compassion in providing space in the conversations for the grief, anger and whole range of emotions that COVID-19 visiting restrictions produce is valued and we also need to extend that compassion to ourselves.

Kerry 06:53 PM **Q. Jeff, are you finding that if there is a documented Advance Directive, that the health care team might not follow it as they are concerned that they have not have a "proper" conversation to come to those conclusions?**	Jeff Myers: Thanks so much Kerry. The issue with advance directives is a patient or their SDM cannot know ahead of time the healthcare context in which a decision might be applied. This is an example scenario: a patient concludes they "do not want machines"; cut to two years later when pt's spouse brings patient to the ED with confusion and shortness of breath. The patient lacks decision making capacity and ED physician says to spouse they're confidant the patient can recover but might need to be intubated for a few days. The wife is now in the difficult position of a "no machines" directive and a "machines will be brief" recommendation. Better information for the spouse two years earlier would be an exploration of how the patient arrived at this conclusion and why. This gets at the underlying values, which can be applied by the SDM in more diverse contexts. Cari Hoffmann: Another challenging area & the laws in this area differ across the country. Suggest you become well versed in the laws in your province/territory & review: https://www.advancecareplanning.ca/resource/living-well-planning-well-lawyers-resource/ https://www.advancecareplanning.ca/resource/living-well-planning-well-resource/
Tara 06:53 PM **Q. NB has a trial going on with a shared care plan in the home of Extramural community patients. Definitely helpful for continuity. Palliative care at home is so busy now with people wanting to stay home who normally would have gone in. What online resource is there for family to help care for palliative patient at home?**	Jessica Simon: Canadian Virtual Hospice has many of those resources. www.virtualhospice.ca Ask in your local area too, One example of local resources in Calgary, AB includes https://ecme.ucalgary.ca/wp-content/uploads/2020/04/Provincial-practical-tips-for-family-when-considering-discharge-home.pdf
Laurie 06:53 PM **Q. When you get to the point in ACP when you do want to discuss concrete decisions**	Cari Hoffmann: Language is so important here. Leaving the space open for patients or HCP to decide independently is not the aim, rather shared decision making. I like this illustration from

like CPR, do you have any strategies to introduce the topic to patients which allow us to make concrete suggestions (ex: we would not recommend CPR in your case) vs leaving the decision very open to patients? I find this challenging … **Yes see the language at the back of the SIC guide adapted for your jurisdiction, for example.**	Plan Well: https://planwellguide.com/serious-illness-decision-making/  It's important to remember: • Just because you want something doesn't mean you will always get it. The medical treatments you receive depend on your values and preferences, but also your illness, your doctor's recommendations, and how you are doing. Your health care team will consider your values and preferences and make decisions with you or your Substitute Decision Maker – the person you choose to speak for you if you couldn't speak for yourself. Making Decisions with Your Doctor(s) YOUR VALUES YOUR PREFERENCES MEDICAL PROBLEM i.e. major heart attack DOCTOR'S RECOMMENDATION SHARED MEDICAL DECISION There are lots of resources, here are a few go-tos : https://www.advancecareplanning.ca/resource/cpr-decision-aids/ http://amytanmd.ucalgaryblogs.ca/files/2020/04/Guide-for-Talking-about-Wishes-Goals-with-COVID-19-Handout-by-Dr.-Amy-Tan-v3.pdf
Lindsey 06:59 PM **Q. A great challenge as a community nurse is when patients are sent home with the phrase of 'get your affairs in order'. It puts a lot back on us at times in many different aspects.**	Jessica Simon: It is indeed a lot to unpack. Being able to guide patients and families through what that means for them can include advice to create an advance directive (or whatever your jurisdiction's document is called). Having a Serious Illness Care conversation can help them express their values and you can document their responses for other HCP to use when needed. Cari Hoffmann: Walking along side patients & families through the 5 steps of ACP I find quite helpful. Helps to manage and often overwhelming process. https://www.youtube.com/watch?v=mPtu-FpY1Kw&feature=emb_logo
Adele 06:25 PM **We are hearing from families different scenarios. protocols and guidelines that have changed due to COVID and public not informed: I.e. Hgb levels are at 70 and no transfusions (stock piling?)**	Jessica Simon: Indeed! One of the challenges in the pandemic is rapidly changing availabilities/protocols etc. and these conversations can explore the fear/uncertainty and how flexible someone might want their named decision-maker to be in describing their values if they cannot speak for themselves.

Michelle 06:29 PM **Do some hospitals have a standard form they use to document the conversation for providers? Do you find this helpful?**	Jessica Simon: Yes the standard form for the conversation documentation that the patient keeps with them and is readily accessible to their next provider means these conversations aren't buried and lost in progress notes of inaccessible in a clinic. Cari Hoffmann: If you are looking for an examples: http://medicalstaff.fraserhealth.ca/getattachment/Clinical-Resources/Strips/Forms/Forms/Advance-Care-Planning/FHA-ACP-RECORD-fill-and-print_FINAL_14-4-2020.pdf.aspx/ https://www.albertahealthservices.ca/frm-103152.pdf
Muriel 06:44 PM **Is it possible to do SIGC virtually?**	Jessica Simon: Yes you can have these conversations virtually - with a digital view like Zoom it is much easier as you can use nonverbal cues. Phone is a challenge but if you already have a relationship with the patient you can overcome that too.
Sandra 06:50 PM **Are there any virtual teaching tools that are available to teach clinicians about a ACP and SI GOC.**	Jessica Simon: There are some videos you can watch that model conversations using the tools. Search Providence Health or go to the Ariadne Lab website to view some of these virtual teaching tools.
Kelly 06:57 PM **Just a comment I think if we take a breath before we speak with patients before chatting with them re: HCD and ACP and truly speak from the heart. Be human. We are great at being clinicians with respect to disease and treatments. If we for a moment have empathy and just be real and honest with self and patients, I think the real es will be captured.**	Jessica Simon: Completely Kelly! Well said.